

# The Navigator

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## Capturing the BEAUTY of our Children

Many parents of children with disabilities are afraid to take their children to a professional photographer. Some fear they won't work well with their child. But, with the right photographer, those fears can be overcome.

Capturing a child's precious smile goes a long way. Missy Tillman, a skilled photographer, and someone who has almost 20 years of experience working with people of varying abilities, is one of the few people who has special skills to do both! It is her passion...

Missy says, "I cannot imagine myself doing anything different. I also love photography and have dabbled with it for nearly 10 years." Missy's portraiture style is very relaxed and informal, which really provides an opportunity for the children's' personalities to shine through. The result is images of happy, playful kids. Her mission and purpose is to capture the true beauty and essence of your child. She also says, "Taking photos of children who have special needs is different for many reasons; there needs to be patience, understanding and compassion. You need to have an open mind and just go with it. There are no boundaries or rules."

Family Voices is Partnering with Missy to offer a FREE SITTING for your loved one with a special health care need. Most sessions are a 1 hour time frame. Within one week of your session, you will get an email with your photos. Missy assures that your session will be in a relaxed, worry-free setting and she will be ready to capture that moment! Missy's sessions



are booked outdoors, for natural lighting. If you are interested in this amazing opportunity, or would like more information, contact Missy at: [new.viewphoto2016@gmail.com](mailto:new.viewphoto2016@gmail.com)



## To the Red Haired Girl at the Splash Pad Who Asked About My Daughter...



Follow  
My Blog

I saw you with your frizzy red pigtails, freckled face and soaking wet yellow dress. I saw you watching my daughter. I saw you sitting near her, not too close, but close enough to watch her expression as she concentrated on watching the buckets fill with water and then pour down. Most kids would be standing under that water. Mine likes to watch from a distance. I saw you smile at her. And then I saw you look up at me. You walked to me, shivering in the air. And you smiled this beautiful, crooked smile with your front teeth missing. I smiled back. And you sat next to me and watched my daughter again. Here is where I brace myself as a mom.

My daughter has Down syndrome. She's nonverbal and may be on the autism spectrum. She doesn't know how to relate to other kids, sometimes doesn't mind just watching others. Some kids watch it and ignore it. Some kids ask questions; *What is wrong with her? Why doesn't she talk? Why is she mean?* (if she pushes somebody too close to her out of the way) *Why is she yelling?*

As her family we are used to these behaviors. The kids she has gone to school with for the past few years know her quirks. But new children are rarely accepting of a child with special needs. Especially when she's 9 and doesn't speak. So I braced myself when you looked up to me. "Is that your daughter?" you asked. I said yes. "What is her name?" And with that reply you got off the bench and went back to sit by her. "Hi!" you said brightly, plopping yourself on the cement right next to her. She looked at you, but instead of shrieking, she smiled back. You wrapped your arm around her and laughed as the water bucket poured down. She looked at your arm, and I stood up, expecting her to shriek and push you away. See, she generally doesn't like being touched. But my daughter, like me, sensed your beauty. Instead of yelling "no!" she did something amazing. She leaned in and hugged you back. And laughed as well. And I sat down again. You were too far away for me to hear your conversation. But I saw you talking to my girl. And not caring if she didn't reply back. I saw you both laugh. I saw her touch your red hair and smile.



When your mom called you, you walked over to me wrapped up in a beautiful handmade quilt. I smiled again, as I was still speechless. Instead of me thanking you, you thanked me as your teeth chattered. "Your daughter was so much fun to play with! Have a great day!" you chimed as you started to run to your mom. I'm sorry I couldn't say thank you at that moment. But, you see, I rarely see friends with my daughter. You gave us the most beautiful gift that day. You gave us a day of making friends and laughing. For that I will always be grateful. And I hope I see your frizzy red pigtails again. This time I will make sure to thank you.

Follow this journey on *My Life With Three*  
<https://mylifewiththree.wordpress.com/>

Did you know that more than 7,500 enrollees in North Dakota were new to the exchange for 2016. Did you think this number was high? Total enrollment in private plans through the Health Insurance Marketplace in North Dakota is actually lower than every other state except Hawaii, but that's to be expected given North Dakota's low population and small number of people eligible to shop in the Marketplace.

[illegible]

- ◆ You'll get the health care you need, when you need it.
- ◆ You'll get free preventive care such as vaccines, screenings, and check-ups.
- ◆ You'll get coverage for prescription pharmaceuticals, emergency care, doctors' visits, and many other health care services.
- ◆ You'll get coverage for pre-existing health conditions that might have kept you from getting coverage in the past.

You can apply for Insurance Marketplace coverage three ways. Online, by mail, or in person with the help of a Navigator or other qualified helper. Family Voices has several trained Navigators throughout the state that are available to assist you. Please call our toll free number to get connected: 1-888-522-9654 **HealthCare.gov** Copyright ©1994-2016, healthinsurance.org llc., Copyright © 2016 North Dakota Insurance Department

LetterReflex assists in overcoming Letter Reversals & Backwards Writing in Early Childhood. If you have a child with dyslexia or a preschooler who is frequently mixing up their b's and d's or p's and q's, this app helps with recognizing letter reversals by having kids play two different games. In the first, which uses the tilt aspect of the iPad, kids direct marbles into the holes formed by b's, d's, p's, and q's. In the second game, kids flip words that are formed incorrectly to match a target word.

## How to Organize Paperwork for your Special Needs Child

With the new school year, comes a lot of papers; forms to sign and keep, teacher information, class lists, school calendars, therapy schedules, after school activity paperwork, immunizations/medical records, etc. This can become very overwhelming and a pile that can stack up quickly. So how much of this paperwork do you keep? All of it, some if it? There's a few pointers to assist in knowing what's important and what you may not need. You need a simple, foolproof document management system.

1. Start by gathering all documents that relate to your child. Bring all paper in boxes, file folders, and bags together in one place. Begin by organizing the documents by year. When you find duplicate documents, compare the duplicates, decide which document has the best photocopy quality, and use this as your master. Many parents say that when they organize documents, they begin to read and are sidetracked. Force yourself to stick with this job until you finish. Do not stop to read the documents. Just date and organize!
2. Hole-punch, then file all dated documents in a large three-ring notebook. When you hole-punch, be careful that you do not destroy important signatures or dates. When documents are formatted horizontally, hole-punch on the top edge. You can also file the information about your child in divider folders, or a system in a file cabinet. Remember to label each year on the binder or file folder.
3. File all documents in chronological order, oldest document on top and newest document at the end. Some parents use the child's birth certificate as the first document in the file. The last document is the most recent piece of information.
4. Try not file documents by category (i.e., IEPs, psychological evaluations, correspondence, etc.). Trying to figure out categories is confusing and time-consuming. If your system is confusing and difficult you won't be eager to use it. After you complete Step 3, review your child's Master File from beginning to end. When you read the information chronologically, you will see the big picture and learn about your child's disability, medical and educational history. This is an important step in becoming an "expert" on your child.
5. You have now dated the documents and filed them in chronological order, oldest document on top, most recent on the bottom. Now you need to create your Master Document List. To create this List, make a table with four columns and label them; Date, Author, Type, and Significance. For a PDF of this table, use the following link: <http://www.fetaweb.com/03/format.doc.list.pdf> Cited: *The Special Education Survival Guide by Pam & Pete Wright*
6. So now that you are prepared, put it into a Care Notebook. A Care Notebook helps you organize the most important information in a central place and makes it easier for you to find and share key Information with others who are part of your child's care team. Family Voices of ND has a Care Notebook that is very user friendly and can travel with you! You can find it at the following link:

<http://fvnd.org/site/wp-content/uploads/2012/11/FVNDCareNotebookWordVersion.2741146003.pdf>

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## Please help us Update your Contact Information



Do you receive the weekly E-News that comes out on Fridays via email from Family Voices? This is a weekly update of state-wide happenings ranging from activities, camps, new services, legislative updates and parent/family trainings.

If you were once getting the E-news and are no longer are receiving it, or if you would like to be added to the E-newsletter, please drop us an email at [fvnd@drtel.net](mailto:fvnd@drtel.net). Many emails have changed and several bounce back, so we want to make sure you're not missing out on these important updates!

Also, the same goes for our list serve. If you are signed up to receive information from our mailing list and no longer are receiving information from us, please let us know! You may be missing out on the trainings being offered, updates about happenings in your region or important legislative and Department of Human Services updates!

Let us know if we can assist you further so we can help keep you informed! *Thank You for helping us assist you!*



### **Our Mission:**

*Family Voices of North Dakota (FVND) aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, Family Voices provides families tools to make informed decisions, advocates for improved public and private policies, builds partnerships among professionals and families and serves as a trusted resource on health care.*

### **Our Vision:**

*Every child and youth with special needs receives family-centered care.*

## Board of Directors

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## 10 Things to Know about Going Back to School

1. **Back to School.** Summer has ended and teachers and students are back to the classroom. This can be a stressful time, but there are ways to make the transition easier. These include making sure to allow time for your child to adjust to changes in routine and wake-up and bedtimes. The new school year means new teachers, classmates, and for some students, a new school. It's important to realize that some students, including those with learning disabilities, may need to use different learning strategies. A range of tools and techniques are available to help meet the needs of students with disabilities at The Child Mind Institute (<http://childmind.org/>) and has tips to help parents prepare their child for changing schools, especially for those with learning or other disabilities. They include assistive technologies, adapted teaching methods and alternative communication strategies.
2. **IDEA and Section 504.** Some of the most important special education services are required by the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973. IDEA ensures that school-age children with disabilities receive a free and appropriate public education. It also provides for special education services, including an individualized education program (IEP). The IEP contains goals for the student and spells out the services that will be provided, which are decided by a team of individuals involved in the student's education. A Section 504 plan can be an alternative to the IEP and outlines how a child's specific needs can be met with modifications and services to remove barriers to learning. So, how are these two laws different? The 504's definition of disability is broader: a child is eligible if they have a mental or physical disability that limits major life activity, a record of the disability or is regarded as having a disability.
3. **Finding Homework Help.** When the school day is over, it's time to get started on homework, which can sometimes be a source of frustration and anxiety.
  - ♦ Friendship Circle, a Michigan-based nonprofit organization, has a blog post that includes "Nine Tips to Make Homework Manageable." <http://www.friendshipcircle.org/blog/2013/12/10/a-special-needs-guide-to-homework/>
  - ♦ LD Online also offers a variety of articles to help children and youth with learning disabilities with note taking, time management and learning strategies. <http://www.ldonline.org/>
  - ♦ Understood's "Homework & Study Skills" section includes an article on "7 Tips for Improving Your Child's Homework & Study Skills." Ideas include creating a designated "homework station", using a color-coded system to organize schoolwork, and if disorganization affects your child's ability to succeed in school, there is a video for ways to improve organizational skills. <https://www.understood.org/en/school-learning/learning-at-home/homework-study-skills/7-tips-for-improving-your-childs-homework-and-study-skills>
4. **Antsy about Tests.** Feeling very nervous, anxious or stressed when it's time to take a test in school is known as "test anxiety." This is a common experience among students, but there are many ways to reduce these feelings. Students with disabilities and their parents should know about the types of accommodations they can request to make test-taking more accessible. These can include extra time on tests, distraction-free rooms and alternative testing methods. Talk to your local school and education team to find out what accommodations can be made or arranged for your child.
5. **The Basics about Bullying.** According to PACER's National Bullying Prevention Center, studies show that children with disabilities experience bullying more frequently than children without disabilities. Bullying can affect a child's ability to learn. There are federal laws that protect children with disabilities from bullying. The U.S. Department of Education also has guidance on keeping students with disabilities safe from bullying. For more information, visit [StopBullying.gov](http://StopBullying.gov).

## 10 Things to Know about Going Back to School Continued...

6. **Service Animals in Schools.** Service animals assist people with sight or hearing issues, mental health disabilities, seizure disorders, autism and other disabilities or health conditions. There are several federal civil rights laws that protect the rights of people who use service animals. The Americans with Disabilities Act (ADA) guarantees a student with a disability has the right to use a service animal at school. However, the IDEA and Section 504 of the Rehabilitation Act provide for the use of an animal that doesn't meet the ADA definition of a service animal if that student's IEP or Section 504 team decide the animal is necessary to meet the student's educational needs. Check with your state's protection and advocacy agency if you have any questions or concerns about the use of service animals in schools.
7. **Eating Right at Lunchtime.** Getting kids to eat healthy foods can be challenging for parents, however, some kids may have certain dietary restricts or aversions which need to be considered when planning or eating school lunches. You may decide packing lunches and snacks is a better option for you and your child but if you want your child to have breakfast or lunch at school, talk to them about your child's diet, allergens and/or restrictions.
8. **Inclusive Physical Education.** Physical activity is important for all children, including those with disabilities. Studies have shown that young people with disabilities are more likely to be obese than their nondisabled peers, and exercise is a key part of maintaining a healthy weight. Schools have certain obligations under the IDEA to include students with disabilities in physical education classes. Section 504 of the Rehabilitation Act also contains regulations that ensure students with disabilities have equal opportunities to participate in after school sports. This U. Department of Education guide helps schools provide inclusive and adaptive physical education opportunities for students with disabilities.
9. **Tips for College Bound Students with Disabilities.** Starting college can be an exciting time, but it comes with a unique set of challenges. There are several things students with disabilities can do to make the transition to college go more smoothly. One is to contact their college or university's disability student services office to learn about supports and accommodations for students with disabilities. Be aware that IDEA no longer covers students once they've graduated from high school. Legal protections for post-high school students are covered under the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act.
10. **Learning to Speak for Yourself.** If you're a student with a disability, self-advocacy skills are important for you to develop as you grow older. There are three key parts to being a self-advocate in school. First, know your needs. Then, learn what accommodations can support your needs. Finally, learn how to communicate your needs to teachers. "Youth in Action! Becoming a Stronger Self-Advocate" helps students with disabilities learn more about self-advocacy. An especially good time to practice being a self-advocate is during IEP meetings. This can help you as you begin to prepare for finishing high school or college. If you're getting ready to graduate from high school there is a guide from the National Collaborative on Workforce and Disability (NCWD) for Youth that is a great tool for thinking about the next steps. Students just starting or getting ready to graduate from college can read the "Self-Advocacy Handbook for College Students with Disabilities" to prepare for the future. There are also resources and organizations for self-advocates with specific types of disabilities, including spinal cord injuries and autism. Visit Self Advocacy Online to learn more.

## 2016 Family Leadership Institute

Family Voices of North Dakota held a Family Leadership Institute for children with special health care needs. The most recent retreat was held June 9-11, with 24 individuals from across the state attending the 2016 Empowering Families as Leaders Retreat! This event is hosted by FVND through a grant from the North Dakota State Council on Developmental Disabilities.

Local, State and National speakers attended the weekend. The purpose of the Retreat is to provide family members with the tools to expand their grassroots advocacy efforts through coalition building, mentoring activities and includes capacity building and knowledge regarding policy, increasing awareness of the impact of health issues and services for Children and Youth with Special Health Care Needs, promoting family/professional partnerships, increase the families' ability to navigate the complex service system and provide the necessary skills for family support and leadership.

Often times, families are just meeting new families who are experiencing some of the same issues as they may be. Some may have never been apart from their child with special health care needs; some have cultural differences; Moms as well as Dads participate. This year, not only was a retreat provided, but several sessions of extended learning and assignments were also given in an year long process. This year the ND Council on Developmental Disabilities extended the contract which will enable us to work 1:1 on new leader's personal goals and objectives and continue to learn about leadership opportunities and participation in the legislative session. Families learn a lot about systems and how they operate from a federal, state and local level. Additionally, they also learn much about their own interpersonal skills that they have and the importance of taking care of self. Outcomes are tremendous.

These new family leaders have gone on to do great things in their own local communities, in the state and national efforts. From starting their own support groups within their own area, accepting positions on school boards and state committees, becoming state employees, invited to federal committees and even meeting the President of the United States. North Dakota is very fortunate to have the family leaders that have been cultivated by many across the state.

The three state parent organizations and local support make up the team for this event. Staff from Family Voices of North Dakota, The Federation of Families for Children's Mental Health, Pathfinder Parent Center and Designer Genes comprise the team for this event. We could not do this without the hard work of this team. We have been extremely fortunate to have national leaders as well as state agencies, other leaders from across the state and legislators attend and provide a wealth of information to the group. Grant funds support this effort through the ND State Council on Developmental Disabilities and donations. We are forever grateful.





## Care Giver Café'

Care Giver Cafe is a project targeted to caregivers/parents of children and youth with disabilities, chronic health and special needs, to provide a tool kit for the daily and long term issues of caring for their child. It is critical to prepare and plan for the future by implementing activities, identifying specific needs, providing local and community resources, to create and sustain a plan for their child into adulthood and planning for unexpected situations, emergencies, and networking with other caregivers. Family Voices of ND originally received a grant from the Consensus Council to pilot the program and then received a grant from Autism Speaks to provide training to families with children and youth on the Autism Spectrum Disorder. This training was done in the cities of Bismarck, Fargo, Grand Forks, Minot and Belcourt. This training is applicable to all families who have children and youth with special needs. If your organization or agency is interested in this training or have questions please contact Family Voices of ND at: 1-701-493-2635.



## New Playgroup in Fargo!

Music Therapy in Motion and the Experienced Parent Program is pairing up with kiddos in the Infant Development Program to improve the quality of life by using the music as the stimuli to address the developmental, medical and/or wellness goals. Benefits of the playgroup are: gross and fine motor skills, expressive and receptive communication skills, socialization, sensory integration and relaxation and wellness just to name a few. Come and enjoy music, some social time out and connect with other parents!

### Time/Dates/Place:

Wed Sept 21 at 11 am and October 26th at 11 am for an hour.

Playgroup with Music in Motion– Fargo Location

6046-B 14th St. S, Fargo, ND 58104

Please call or email Maria Peralta with any further questions or information you may have at: (701) 793-3141 or email

[maria58078@hotmail.com](mailto:maria58078@hotmail.com)

This is a free session offered to children in Infant Development.



## 3rd Annual ND Autism Spectrum Disorders Conference

The 3rd Annual ND Autism Spectrum Disorders Conference will be held on October 26-28, 2016 at the Grand Hotel in Minot, North Dakota. The Anne Carlsen Center in partnership with the ND Department of Human Services, is hosting the Conference. This is an amazing opportunity to educate parents, therapists, teachers, medical professionals, and first responders about autism. This conference has something for everyone whether you are new to autism or are looking for new techniques to provide support. Tracks include: Parents, Educators, Providers, First Repsonders (Thursday only), and Medical (Friday only). Days are full days (8:30am-4:45pm) with lunch included each day. Attend all three days or just one day, whichever works best for you. Space is limited so register today!



<http://www.continuingeducationassociates.com/asd-conference-registration>

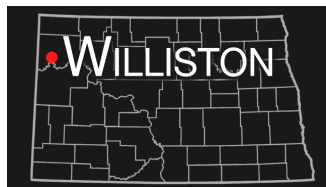
## Williston area Happenings

Spring and summer was a wonderful and busy time in Williston! The city and private groups set up several events for family activities and fun. Family Voices staff, volunteers and Board members were in attendance at many of these events.

One event that stands out was The Week of the Young Child™ in April. The event is sponsored by the National Association for the Education of Young Children (NAEYC). It is the world's largest early childhood education association, with more than over 60,000 members and a network of nearly 300 local, state and regional affiliates. Over 1000 people showed up for an all-day free event for children and their families. Families were able to visit with various agencies and groups both public and private to see how they service individuals and children in our community. All children in attendance left with goody bags full of toys and candy, some even walked away with bikes, scooters and radio control cars. The Week of the Young Child™ is an annual event celebrating early learning, young children, their teachers and families. *Citing: © National Association for the Education of Young Children - Promoting excellence in early childhood education 1313 L St. NW, Suite 500, Washington, D.C. 20005 | (800)424-2460 | webmaster@naeyc.org*



The 2016-2017 school year just started and the students in Williston have 2 new schools to be proud of; Bakken Elementary and the new Williston high School. The High School will offer a new program for students within the new Career and Technical Education Building offering classes in; nursing, certified nursing assistance training, agriculture, automotive repair, carpentry/building and butchery. These classes will give all students a kick start into careers and allow students an opportunity they didn't have previously. With the new classrooms and options offered at the high school, the Special Education department will also give students with special health care needs and different abilities, more options and choices as well. Both schools have been received proudly and with much anticipation by the students, parents and the community.



If you would like more information on Family Voices in the Williston area, please contact Heather Wheeler at: [ayla774@yahoo.com](mailto:ayla774@yahoo.com) or you can call her at (701) 580-7333.

## Grand Forks area Happenings

For our Teen Night Out event, the teens were invited to a special day of the "Hooked on Fishing" event in June. They enjoyed a beautiful, very warm, July afternoon at Turtle River State Park. Another Teen event planned was a day at the East Grand Forks swimming pool and Sherlock Park on August 18th! Fun was had by all.

It is hard to believe school has started and we are now in the planning stages for the annual "Trunk or Treat" and "Special Visit with Santa" events. If I can be of assistance in any way, in the Grand Forks area, please contact Joan at 701-330-8641 or email: [joankarpenko@hotmail.com](mailto:joankarpenko@hotmail.com)



## Fargo Trunk or Treat Date Set!

Fargo's Annual Trunk or Treat has been set for Sunday, October 23rd from 1-3pm at Dakota Medical Foundation.

This is the day children can "Trunk or Treat" without barriers (no doorbells to ring, no steps to climb, in day light hours) and is designed for children with special health care needs and/or a disability, their families and friends! This is an inclusive, free-event and is available for ALL children in our community.



Many businesses, area agencies and local families participate in this fun event! The fee to register a Trunk is \$50 and some candy or trinkets you would like to pass out. The best decorated Trunk wins a \$100 gift card! If you are interested in hosting a trunk or would like more information, please contact Tonya Oss-Brewer at [tonyaob@yahoo.com](mailto:tonyaob@yahoo.com).

## Anne Carlsen Center's 75th Anniversary Party!

It's time to celebrate the Anne Carlsen Center's 75th birthday!! We are kicking off the birthday festivities on **September 23 at the Jamestown Campus**. The following events are free and open to the public!

### Community Breakfast and Presentation:

- Time: Serving starts at 8:30 -9:30 AM
- Location: Jamestown Campus Gymnasium
- Menu: Egg bake, quiche, yogurt parfaits, pastries, coffee and juice
- Presentation: 9:30am- including entertaining stories about the Anne Carlsen Center from the executive teams, families and current and former employees.
- PBS Movie: We will also be airing the PBS Movie – Anne Carlsen: Handicapped Hall of Fame 1985
- Expo Area: During breakfast, the expo area featuring the vendors with which the Anne Carlsen Center does business. Each program within the Anne Carlsen Center will also have a booth that provides more insight into their program.
- Tours: We will have tour guides on hand, so if someone you know would like to know more about what happens at the Anne Carlsen Center, point them in the direction of one of our tour guides.

### Family Movie Night:

Did you know the movie Dumbo was released in 1941, the same year that the Anne Carlsen Center started serving children and their families? Bring your family and friends back for a premiere showing of Dumbo, popcorn, cotton candy, pop and water at the Jamestown Campus Gymnasium from 6-8pm.

This a memorable birthday year for the Anne Carlsen Center, the residents and their families and the communities that the Anne Carlsen Center serves. With that vision, they are planning to make this a progressive celebration and will be hosting this same type of event in Fargo, Grand Forks, Bismarck, Minot and Devils Lake, in conjunction with our Donor appreciation lunches. Stay tuned for more information as plans are finalized and watch for an invite coming your way soon!



Anne Carlsen  
CENTER  
Nurturing abilities. Changing lives.

Donene Feist, Director

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Find us on the Web!

<http://fvnd.org/>

"Supporting Families having children with special health care needs and disabilities and the providers who provide care for them"

## Want to Make a Difference?

You could help us by assisting in workshops, writing articles, being a Support Parent and much more...Or you can provide a Donation by making a contribution to FVND which will assist with workshops, matching parents for emotional support, Regional Parent Navigator Teams and much more!

\_\_\_\_ To be used where needed      \_\_\_\_ Endowment

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Donation of \_\_\_\_\_ \$250 \_\_\_\_\_ \$100 \_\_\_\_\_ \$50 \_\_\_\_\_ \$25 \_\_\_\_\_ \$10 \_\_\_\_\_ \$5

Fill out this form, cut out and mail to: Family Voices of North Dakota  
PO Box 163, Edgeley, ND 58433

### We Want to Thank Our Professional Partners

This newsletter is funded in part by the ND Department of Health, Children's Special Health Services, ND Dept. of Public Instruction, North Dakota State Council for Developmental Disabilities, and the Maternal and Child Health Bureau 1H84MC07992-01-00